DOCUMENT RESUME

ED 322 704 EC 231 898

TITLE	Quality Assurance Resources: Instruments, Organizations and Publications.
INSTITUTION	Association for Retarded Citizens, Arlington, TX.
PUB DATE	Oct 89
NOTE	21p.; Prepared by the Program Services for Children and Adults Committee.
AVAILABLE FROM	Association for Retarded Citizens, 2501 Avenue J., P.O. Box 6109, Arlington, TX 76005 ($2.00).
PUB TYPE	Reference Materials - Directories/Catalogs (132) -- Viewpoints (120)
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	*Delivery Systems; Evaluation Methods; *Mental Retardation; Organizations (Groups); *Program Evaluation; *Quality Control; Standards
IDENTIFIERS	*Association for Retarded Citizens

ABSTRACT

The directory contains a list and description of 20 quality assurance instruments, 5 organizations, and 10 publications to aid in monitoring service delivery systems for people with mental retardation. A position statement by the Association for Retarded Citizens on the multiple dimensions of quality assessment precedes the list. It stresses important assessment components including asking mentally retarded individuals about their preferences, determining levels of satisfaction from family and friends, applying measures of outcomes, and determining relevance and functionality of goals and objectives within individual plans. Information for each listing includes, where possible, a description, cost information, name of a contact person, address, and telephone number. (DB)

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Quality Assurance Resources

Instruments, Organizations and Publications

ARC Department of Research and Program Services

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Prepared by
the ARC of the United States Program Services for Children and Adults Committee

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PREFACE

An ongoing goal of the **ARC** has been to advocate for quality community services for those with mental retardation. To pursue this course, the **ARC** has established an array of service objectives specifically addressing the many facets of service delivery, legislation, and community action through our chapters, including an objective pertaining to quality assurance.

In 1988, the **ARC** collected and reviewed various quality assurance resources. **ARC** chapters and other organizations around the country were contacted and solicited for evaluation instruments, publications, and related information on exemplary monitoring tools and programs. A bulk of information was received, reviewed, categorized, and assembled into a booklet. The collection of resources has continued, and a revised addition of the quality assurance resources booklet has been developed.

It's my desire that each of you explore and use the contents of this booklet. And it's my hope that your **ARC** chapter benefits by gaining an increased knowledge of quality assurance. The end result of this work and the endeavors that you put into quality community services will ultimately lead to a better society for our sons, daughters, family members, and friends with mental retardation.

Barbara L. Sackett, President
ARC of the United States

INTRODUCTION

The following pages contain a list and description of quality assurance instruments, organizations, and publications to help you secure resources for monitoring service-delivery systems for people with mental retardation.

We attempted to include instruments or components of instruments in this list which are considered model by experts or were provided by **ARC** chapters and other organizations. No system was employed to guarantee every instrument is truly exemplary. However, each person submitting an instrument found that their tool was useful for assessing services.

We also included in our list a number of organizations and publications which directly or indirectly address the monitoring of services for people with mental retardation. You are encouraged to review the literature and contact different organizations so as to familiarize yourself with quality assurance tools and standards. Select a monitoring instrument to use only <u>after</u> careful examination of the components of a quality system which meet your needs and those of your community.

The quality assurance resources in this list will be periodically reviewed and updated. The **ARC** encourages you to submit new resources for review and possible inclusion in future revisions of this list. Send to:

Department of Research and Program Services
Association for Retarded Citizens of the United States
P.O. Box 6109
Arlington, Texas 76005

October, 1989

ARC POSITION

Quality

ISSUE

The rapid expansion and diversification of services for people with mental retardation has led to increased concern about how to define quality and how to assure quality.

In the past, quality has meant compliance with minimal standards such as physical space, staff ratios, written policies and processes. While improving federal and state standards remains a common approach to define and assure quality, we must now confront the more elusive elements of quality.

The Association for Retarded Citizens has always articulated value-based principles such as individualization, respect, dignity, freedom from harm, integration (participation), independence (interdependence), and productivity (contribution). Emphasis on the individual must continue to be the ongoing focal point of quality.

POSITION

The ARC believes that quality must be viewed as a multidimensional concept. We believe that the ARC should work to assure that a multidimensional system for ensuring quality is in place and functioning effectively. Fundamentally, quality begins with the individual with mental retardation in terms of frequent and direct measures of satisfaction and outcomes. All individuals with mental retardation should, through formal and informal interviews or observations, be asked about their satisfaction and preferences regarding services, supports and other aspects of their lives. In cases of people with multiple or sensory impairments, alternative methods of communication should be used.

A second level of quality is the satisfaction of family, advocates and/or friends. In some cases, the views of family, advocates and friends may be in direct conflict with the individual's preferences. In these instances, respect, dignity and protection from harm must be carefully considered in resolving differences.

A next level of assess-

ing quality is to rely on measures of outcomes such as levels of productivity or contributions, integration or participation and independence or interdependence. These measures provide a progress report on how well the individual is doing.

A fourth level of quality is to ask questions about the relevance and functionality of goals and objectives within the individual plan. These questions can be raised during the periodic reviews of individual plans.

Independent case management/service coordination provides another level of monitoring quality through involvement in the assessment, planning, implementation and evaluation of services and supports for individuals with mental retardation.

The sixth level of monitoring quality is periodic visits and checks by families, friends and advocates on the humaneness of services and supports. This important approach is often called citizen monitoring. Finally, state licensure, federal certification and national accreditation are traditional means to assure compliance with standards of health, safety and rights.

The ARC must be a catalyst for bringing about a value-based cohesive, consistent and coherent system of quality which better defines the elusive dynamic called quality.

Defining and assuring quality depends on fact finding, interpretation and judgment. How we assure quality depends on how we define quality. By infusing values in all decisions, we will define standards that exceed current professional practice and will require periodic redefinition of "best" practice.

ARC believes that assuring quality is a process that converts evolving values and beliefs into quantitative and qualitative assessments. ARC must advocate for increased empowerment of individuals and families in this process.

Defining quality is a dynamic process. This process is inherently difficult because beliefs must be translated into surveys and instruments. The state of the practice usually lags behind the state of the art.

The process of thinking and caring about quality is essential to achieve quality. For example, the process of seeking and preparing for accreditation may be more important than achieving accreditation. The process of citizen monitoring may be more important than the report of findings. Organizational commitment and actions toward quality actually lead to definition and redefinition of what constitutes quality.

INSTRUMENTS

A GUIDE TO PROGRAM QUALITY REVIEW OF DAY PROGRAMS

A check-list instrument to assess day programs for people with mental retardation. The instrument determines if programs are near community resources, allows people to develop relationships with co-workers, helps people make plans and choices, respects people's rights, and helps develop special skills and interests. Reviews are done by teams consisting of a person with mental retardation, family member, staff person, and funding personnel. 1986.

No cost.

Contact - **Dr. Charles Galloway**, Connecticut Dept. of Mental Retardation, 90 Pitkin St., E. Hartford, CT 06108 (203)528-7141

ASSOCIATION FOR RETARDED CITIZENS GROUP HOME SATISFACTION SURVEY

A 62 question rating instrument for parents or guardians of people with mental retardation in group homes. The mail-out survey solicits the perceptions of parents/guardians on group home services using a one to five scale on 56 questions and asks for comments on six questions. 1988.

No cost for single copies.

Contact - **ARC/New Mexico**, 8210 La Mirada N.E., Ste. 500, Albuquerque, NM 87109 (505)298-6796

ASSOCIATION FOR RETARDED CITIZENS OF ARIZONA VOLUNTEER MONITORING TOOL

A check-list approach, designed by family members to determine whether residential community homes for children and adults are quality programs. The monitoring project focuses on the "Would I want to live here?" approach. Volunteer family members and self-advocates applaud positive aspects of homes monitored as well as share constructive ideas for program enhancement. Tool and packet of information on full project is available.

No cost.

Contact - **ARC/Arizona**, 5610 S. Central Ave., Phoenix, AZ 85040 (602)243-1787

ASSOCIATION FOR RETARDED CITIZENS/MICHIGAN MONITORING TOOLS

These monitoring tools are used to create and/or maintain quality living in state run residential settings. The focus is on quality of life and normalization, always putting yourself (the monitor) in the place of the people in residential programs. Tools consist of Group Home Observation Forms, Nursing Home Observation Forms, and Regional Center Observation Forms. Tools are used in conjunction with 12 hours of training and a 75 page monitoring manual.

$20.00 for manual. Reproducible forms can be obtained free by sending SASE.

Contact - **Sandy Orne-Adams**, ARC/Michigan, 313 S Washington Sq., Ste. 310, Lansing, MI 48933 (517)487-5426

ASSOCIATION FOR THE MACOMB OAKLAND REGIONAL CENTER MONITORING GUIDELINES

An outline of the AMORC Monitoring Committee to evaluate and report on residential services. Committee members go out in teams of two people to evaluate area group homes. The evaluation addresses the general areas of quality of life, health, nutrition, and client rights. Each general area lists a number of specific questions to evaluate the program.

$3.00.

Contact - **Ruth M. Taylor**, AMORC Monitoring Committee, POB 471, New Haven, MI 45048 (313)749-3038

CENTER-BASED PRESCHOL-AGE PROGRAM QUALITY REVIEW INSTRUMENT

A rating tool for child development programs. The instrument can be used in self-review, as a teaching tool, as a review of program quality, or for program improvement. The instrument rates the program's philosophy; goals and objectives; administration; assessment of child and family; developmental program; parent education and involvement; community resources and involvement; and evaluation. 1988.

$2.00.

Contact - **Dept. of Education**, Child Development Division, POB 944272, Sacramento, CA 94244-2720 (916)323-1343

CHILD DEVELOPMENT PROGRAM EVALUATION

The Child Development Program Evaluation is a licensing monitoring system that identifies key regulatory predictor indicators that have a positive impact on children's development. Its applicability in the mental retardation service area is in the identification of basic health and safety standards that apply to all human services.
Developed under **Richard Fiene, Ph.D.**, 1981.

No cost.

Contact - **Richard Fiene, Ph.D.**, Dept. of Public Welfare, POB 2675, Harrisburg, PA 17105-2675
(717)257-7295

CLIENT OUTCOME FORMATIVE EVALUATION

A comprehensive system to evaluate the needs and service-delivery system for adults with mental retardation. The system is based on program and client outcomes. The system evaluates in terms of program mission, target population, services provided, client outcome objectives, measures of objectives, application of measures, and extent of expectations. A two-volume program evaluation and training manual is available. 1984.

No cost.

Contact - **Charles Lyle**, Community Human Services Dept., 160 E. Kellogg Blvd., St. Paul, MN 55101
(612)298-5351

COMMONWEALTH OF PENNSYLVANIA QUALITY ASSURANCE SYSTEM

A nationally recognized individual oriented and outcome oriented quality assurance model. In this system, the individual is visited annually, families are surveyed by mail, and both residential and day program/employment environments are measured in terms of behavioral progress, independence, productivity, and integration. The system allows for direct contact with the consumer and remedies for "red flag" situations. 1986.

No cost.

Contact - **James Conroy**, Temple Univ., 927 Ritter Annex, Philadelphia, PA 19122
(215)787-6560 or 6561

CONSUMER PROGRAM REVIEW

The Consumer Program Review is an evaluation instrument which was designed to assist consumers who have a developmental disability, including those individuals who have a cognitive impairment, in the evaluation of day programs in which they and others participate. The instrument utilizes information from the consumer and staff of the program to make an assessment.
By **Joanna Pierson** and **Nancy Norwood**, 1985, revised 1987.

$5.00.

Contact - **ARC-Frederick Co.**, 1315 Orchard Way, Frederick, MD 21701 (301)663-0909

DELAWARE ASSOCIATION FOR RETARDED CITIZENS MONITORING INSTRUMENT

A check-list to monitor residential programs for individuals with mental retardation. Based on quality of life standards, the instrument assesses programs in terms of physical appearance/location, respect and dignity of client, integration, skill development, and personal relationships. Utilizes a three person monitoring team.

No cost.

Contact - **ARC/Delaware**, 240 N. James St. B-2, Tower Office Park, Wilmington, DE 19804 (302)996-9400

GUIDELINES FOR QUALITY INDIVIDUAL PLANS

A brochure check-list to help families and individuals with disabilities assess whether the written individual plan meets state-of-the-art criteria (Note: this brochure was reprinted by the ARC with permission from Minnesota. The ARC brochure contains a list of national organizations to contact for assistance). 1987.

Minnesota: single copies free. Contact for bulk requests. ARC: Single copies free with self-addressed, stamped envelope. $12.50 per 100.

Contact - **Governor's Planning Council on D.D.**, 300 Centennial Bldg., 658 Cedar St., St. Paul, MN 55158 (612)296-4018 or **ARC National Headquarters**, POB 6109, Arlington, TX 76005 (817)640-0204

PARTNERSHIP FOR QUALITY SERVICES

The Partnership for Quality Services Volunteer Handbook and videotape can be utilized as a guide for developing and implementing a volunteer monitoring system or for promoting quality assurance concepts in community programs. The handbook includes the monitoring tool, standards, reporting methods, and background information for volunteers. The video depicts quality of life issues and the monitoring process for training volunteers. 1987.

$15.00 per video tape. $16.00 per handbook.

Contact - **Jean Swanson**, ARC/Minnesota, 3225 Lyndale Ave. South, Minneapolis, MN 55408 (612)827-5641

PASSING

Designed to help meet the demand for incisively measuring the quality of human services in relation to normalization in an insightful and concrete manner. PASSING can be learned and used by most citizens and service consumers as well as service staff. List of evaluation forms available.
By **Wolf Wolfenberger** and **Susan Thomas**, NIMR, 1983. 530 pp.

$40.00 plus 10% postage. Order #1038.

Contact - **The G. Allen Roeher Institute**, Kinsmen Bldg., York Univ., 4700 Keele St., Downsview, Ontario, CANADA M3J1P3 (416)661-9611

PERSONAL INTEGRATION INVENTORY

A survey approach to assessing the extent to which the individual is being integrated into the community. It focuses on the day-to-day experiences and interactions of people who live in community settings and should be completed by someone familiar with the person. The survey can be used every six or twelve months to assess the individual's growth and progress.
By **Hank Bersani** and **Rebecca Salon**, 1988.

$2.10 plus 10% shipping and handling.

Contact - **Rachel A. Zubel**, Coordinator, Publications, Syracuse Univ., 200 Huntington Hall, 2nd Fl., Syracuse, NY 13244-4230 (315)443-3851

PROGRAM ANALYSIS OF SERVICE SYSTEMS (PASS 3)

PASS 3 is a method of assessing the quality of a wide variety of human services for any handicapped or disadvantaged group of people.
By **Wolf Wolfensberger** and **Linda Glenn**, NIMR, 1975, Handbook, 91 pp. Field Manual, 81 pp.

Handbook - $9.00, Order #1249. Field Manual - $10.00, Order #1239. Both - $17.00, Order #1061. Add 10% postage.

Contact - **The G. Allen Roeher Institute**, Kinsmen Bldg., York Univ., 4700 Keele St., Downsview, Ontario, CANADA M3J1P3 (416)661-9611

PROGRAM QUALITY INDICATORS (PQI)

PQI is designed for use by school district personnel and consumer groups to evaluate and guide program development. The check-list monitoring tool is organized into six program components: (1) Program Philosophy; (2) Program Design and Student Opportunities for Learning; (3) Systematic Instruction and Performance Evaluation; (4) IEP Development and Parent Participation; (5) Staff Development and Team Collaborations; and (6) Facilities and Resources. 1987.

$5.00.

Contact - **TASH - Association for Persons with Severe Handicaps**, 7010 Roosevelt Way NE, Seattle, WA 98115 (206)523-8446

RESIDENTIAL SERVICES MONITORING PROJECT

An evaluation instrument and companion handbook to monitor residential services. The instrument publication covers major areas of concern. The handbook contains descriptions of residential alternatives, procedural guidelines, and other pertinent areas. Information on setting up or attending workshops is also available. 1984.

$15.00 per set for ARC members. $25.00 per set for non-ARC members.

Contact - **ARC/Ohio**, 360 S. Third St., Ste. 101, Columbus, OH 43215 (614)228-4412

TEST YOUR IQ: INTEGRATION QUOTIENT

A brochure check-list to help families of persons with developmental disabilities determine the level of integration efforts provided by the programs and services they use.

Single copies free. Contact for bulk requests.

Contact - **Governor's Planning Council on D.D.**, 300 Centennial Bldg., 658 Cedar St., St. Paul, MN 55155 (612)296-4018

TEST YOUR SCHOOL'S IQ: INTEGRATION QUOTIENT

A brochure check-list to help families of students with developmental disabilities determine the level of integration in their local schools. Contains a list of Minnesota organizations to contact for further information (Note: this brochure was reprinted by the ARC with permission from Minnesota. The ARC brochure contains a list of national organizations to contact for assistance). 1987.

Minnesota: single copies free. Contact for bulk requests. ARC: single copies free with self-addressed, stamped envelope. $12.50 per 100.

Contact - **Governor's Planning Council on D.D.**, 300 Centennial Bldg., 658 Cedar St., St. Paul, MN 55158 (612)296-4018 or **ARC National Headquarters**. POB 6109, Arlington, TX 76005 (817)640-0204

ORGANIZATIONS

ACCREDITATION COUNCIL ON SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

A private, non-profit agency sponsored by nine consumer advocacy, professional and service provider organizations (including the ARC). The purpose of the organization is to improve the quality of services for persons with developmental disabilities through the development of standards, provision of accreditation surveys, in-service training/consultations, workshops and publication of educational materials.

Publications and workshops available. Contact for list and prices.

Contact - **ACDD**, 8100 Professional Pl, Ste. 204, Landover, MD 20785 (301)459-3191

AMERICAN CAMPING ASSOCIATION

A national organization that sets standards for accreditation of camps, including those that serve people with mental retardation. A Camp Standards Without Interpretations booklet is available.

$2.95 plus postage. Free Publications Catalog by request.

Contact - **Publications Dept.**, American Camping Association, 5000 State Rd. 67 N., Martinsville, IN 46151-7902 1-800-428-CAMP; (317)342-8456

AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

A national organization that sets standards for accreditation of quality speech-language pathology and audiology services. The organization also sets standards for certification of professionals in the field. Information available includes Accreditation Manual, Interpretation of Standards, and Membership & Certification Handbook.

No cost.

Contact - **Professional Services Board**, American S-L-H Association, 10801 Rockville Pike, Rockville, MD 20852 (301)897-5700

COMMISSION ON ACCREDITATION OF REHABILITATION FACILITIES

A private, non-profit organization established by and for the field of rehabilitation/habilitation to adopt and apply standards in organizations throughout the nation. CARF has standards for a variety of individual programs or services including employment programs, residential services, personal and social adjustment programs, etc. A Standard's Manual addresses organization and program operations based on recommendations by professionals and consumers.

Publications available. Contact for list and prices.

Contact - **CARF**, 101 North Wilmot Rd., Ste. 500, Tucson, AZ 85711 (602)748-1212

NATIONAL ACCREDITATION COUNCIL FOR AGENCIES SERVING THE BLIND AND VISUALLY HANDICAPPED

A national organization that sets standards for accreditation of agencies and schools that serve those with visual impairments. An On-Site Review Guidelines and publications order form is available.

No cost.

Contact - **National Accreditation Council**, 232 Madison Ave. #907, New York, NY 10016 (212)779-8080

PUBLICATIONS

ASSESSING AND ENHANCING THE QUALITY OF SERVICES

A comprehensive overview of the purposes of quality assurance, the current state-of-the-art, the components and elements of a viable quality assurance system, methodological and measurement constraints, and model quality assurance approaches. This manual represents five years of work and analysis and is applicable to developmental and other human services.
Project Director: **Valerie J. Bradley**, 1984, 268 pp.

$15.00 plus postage. Other publications also available.

Contact - **Publications Coordinator**, Human Services Research Institute, 2336 Massachusetts Ave., Cambridge, MA 02140 (617)876-0426

ASSURING RESIDENTIAL QUALITY: ISSUES, APPROACHES AND INSTRUMENTS

A report on several issues in the field of quality assurance. Areas covered include definitions of key terms, the role of ideology, major types of quality assurance, and dimensions of quality assurance. The report also includes an annotated bibliography of measures designed specifically to review integration.
By **Hank Bersani**, 1989, 66 pp.

$3.40 plus 10% shipping and handling.

Contact - **Rachel A. Zubel**, Publications, Center on Human Policy, Syracuse, Univ., 200 Huntington Hall, 2nd Fl., Syracuse, NY 13244-4230 (315)443-3851

GUIDELINES FOR EVALUATORS DURING A PASS, PASSING, FOR SIMILAR ASSESSMENT OF HUMAN SERVICE QUALITY

A guide for PASS or PASSING users for the preparation and conduct of an assessment.
By **Wolf Wolfensberger**, NIMR, 1983, 180 pp.

$20.00 plus 10% postage. Order #1043.

Contact - **The G. Allan Roeher Institute**, Kinsmen Bldg., York Univ., 4700 Keele St., Downsview, Ontario, CANADA M3J1P3 (416)661-9611

MONITORING COMMUNITY RESIDENCES: GUIDELINES - HANDBOOK

Describes the role of the voluntary service monitor, clarifies the meaning of normalization, provides a list of questions that monitors use and contains useful bibliographies.
By **Hank Bersani**, 1984, 53 pp.

$3.25 plus 10% shipping and handling.

Contact - **Rachel A. Zubel**, Publications, Center on Human Policy, Syracuse Univ., 200 Huntington Hall, 2nd Fl., Syracuse NY 13244-4230 (315)443-3851

QUALITY ASSURANCE FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

A book addressing the subject of quality assurance from the perspectives of self-advocates, parents, service providers, evaluators, and scholars. The text is devoted to the many aspects of quality assurance including conceptual issues; varying perspectives; government's role; management and accreditation; and research and the future of quality assurance.
Edited by **Valerie J. Bradley** and **Hank A. Bersani**, 1990, 352 pp.

$29.00 plus approximately $2.50 shipping and handling.

Contact - **Paul H. Brookes Publishing Co.**, P.O. Box 10624, Baltimore, MD 21285 1-800-638-3775 or in Maryland call (301)337-9580

QUALITY EVALUATION GUIDELINES

A publication of the International League of Societies for Persons with Mental Handicap. The book addresses the guidelines for quality services as established by 35 delegates from 18 countries who met for a three day symposium in 1986. Areas covered include: principles, quality standards, evaluation methods, contexts for evaluation, and basic premises and implementation steps. 1988, 37 pp.

Based on foreign currency exchange. Contact for price in U.S. dollars.

Contact - **ILSMH Secretariat**, 248 Avenue Louise - bte 17, B-1050, Brussels (BELGIUM)

QUALITY OF LIFE: MEASUREMENT AND PROGRAMMATIC IMPLICATIONS

A manual summarizing the work to date regarding the development, standardization, and use of the Quality of Life Questionnaire. The authors have been involved in a three-year study on how to evaluate a person's quality of life. The manual addresses the concept of quality of life and its measurement, the development of the Questionnaire, and its use and resulting data.
By **Kenneth Keith, Robert Schalock**, and **Karen Hoffman**, 1986, 54 pp.

$10.00 plus postage.

Contact - **Publications**, Region V Mental Retardation Services, POB 2040, Lincoln, NE 68502
(402)471-4400

QUALITY: AN EXPLORATION OF WHAT MAKES QUALITY RESIDENTIAL SERVICES

A report of the ARC/North Carolina Task Force on Quality. The report is the result of numerous meetings of professionals in the areas of residential care and quality assurance, an extensive research of the literature, and a public hearing on the issues. Areas addressed include the physical setting, the community, relationships, rights, management, program standards, funding, and other pertinent areas. 1988, 20 pp.

$3.00.

Contact - **ARC/North Carolina**, 16 Rowan St., Suite 204, POB 20545, Raleigh, NC 27609
(919)782-4632

SAFEGUARDS: A SYSTEM FOR MONITORING SERVICE QUALITY

Region V Mental Retardation Services serves over 650 people in a sixteen county area. The evaluation system it has developed helps safeguard the individualized services each person receives. This booklet provides a detailed breakdown of how the system evaluates the different program components: regulation, accreditation, systematic communication, procedural protection, systems review, and first line problem solving. 19 pp.

$3.00 plus postage.

Contact - **Publications**, Region V Mental Retardation Services, POB 2040, Lincoln, NE 68502
(402)471-4400

THE PRINCIPLE OF NORMALIZATION IN HUMAN SERVICES

A book which looks at all aspects of normalization and its major implications. It examines normalization in relationship to specific problems and service areas.
By **Wolf Wolfensberger**, NIMR, 1972, 259 pp.

$12.50 plus 10% postage. Order #1016.

Contact - **The G. Allen Roeher Institute**, Kinsmen Bldg., York Univ., 4700 Keele St., Downsview, Ontario, CANADA M3G1P3 (416)661-9611

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